

A patient reflects on chronic illness—and support from family and physicians

Tim Prevou

Note: This editorial was a college essay; the assignment was to write an acceptance speech for an award given for something the student had accomplished. Tim Prevou has been treated since age 6 by Dr. Virginia Pascual, a pediatric rheumatologist and researcher at Baylor Research Institute. Dr. Pascual collaborated with Dr. Carol Wise, who found the mutated gene responsible for PAPA syndrome; she and her team later found that IL-1 blockade was an effective therapy. Dr. Pascual commented: “This therapy completely cured Tim’s twin brothers and completely resolved Tim’s arthritis. Tim’s severe pyoderma lesions took more effort, but eventually we also got them under control. . . . He is the only patient over 18 years old that I still see in the clinic. . . . I am very proud of him.”

Thanks for my award for surviving chronic illness!

Imagine bloody, seeping wounds on your legs. Imagine how they look—so deep you can see the bone, so painful to look at and extremely painful to have. You have to take the strongest pain medicine just to live through the day or to be able to sleep at all at night, and sometimes, when that isn’t enough, you are admitted to the hospital just to control your anguish. Infection is a constant threat, and you feel like you’re living in hell. Now lastly, imagine having this kind of experience every day for 5 years. Well, I don’t have to imagine such a difficult reality because I lived it, from age 10 to age 15.

I’m accepting this award today for surviving years of chronic illness, staying alive and fulfilling my dream of going on to college. For many, this would be a simple feat, not even worth mentioning except in light conversation, but for me to have come this far despite everything is indeed a huge accomplishment and a blessing.

I believe I’ve made it this far for several reasons. First would be my own willpower, for without it I would be lost. Second would definitely be my family, a protective shield that has been with me my entire life and will continue to lend me strength for the rest of it. And third, I have to give credit to my doctors, a team in Dallas who have also fought for me for many years and have always tried their best to bring me comfort and a better way of life.

There are many more people who have helped me along the way, such as some really great teachers and supportive friends,

but my willpower, my family, and my medical team are at the core of my success. To look back on the challenges of the past 19 years is both amazing and painful, but it must be done.

Let me first give thanks to myself and my own strength and sense of purpose, for where there is a will, there is a way. It doesn’t matter how much help you receive if you aren’t able to push yourself forward, right? There were many times that I wanted to give up, call it quits. After all, for a boy of 13, what’s the point in fighting if you feel like you will never again get to play with your friends or play your favorite sports and will always have pain in one way or another?

Human willpower is a strange thing, however. It goes against all logic in some cases, and we draw on it all the time without realizing it. There have been reports of mothers lifting a car to save their child, feats of almost superhuman strength. There are monks in Budapest who can walk on hot coals and can withstand any number of blows to their body, simply because of their mastery of mind over matter. They will themselves to go above the pain and will their bodies to do the same.

Willpower is never to be underestimated, and mine was no exception. Day after day, I would think, “That’s it. I’ve had it. I can’t go on anymore.” But I always woke up the next day and I went to school and went to my constant medical appointments. Then, after 5 years, when the wounds finally healed, thanks to a combination of powerful infused medications, I was still here. I had made it through hell and come out on the other side, stronger and better for having made it through.

Strength of will—it was my ace in the hole, I guess you could say. Sometimes, we don’t even know that we have it in us, this ability to keep on even when we are struggling to stay afloat, whether it be emotionally, spiritually, or financially. So, I do indeed give thanks, first and foremost, to my willpower, without which my life today would not be possible.

My ability to survive and, in some ways, thrive, however, is because of the people in my life who gave me a reason to keep going. That is why, secondly, I want to thank my family, not only for lending me their strength but also for using their own to make sure I would make it through.

Have you ever spent your entire day, and sometimes several days in a row, in a chair in an emergency room? Have you sat

Corresponding author: Tim Prevou (e-mail: nickiprevou@sbcglobal.net).

up, all night long, in an intensive care unit, hoping that your child would survive the sepsis in his bloodstream? Have you given up days, weeks, months, and years of your life to pursue every possible therapy, every possible medicine and procedure that might improve your loved one's quality of life?

Anyone who has endured the chronic illness of someone they love has probably had those kinds of experiences. I'll tell you who has also endured these kinds of challenges: my mom and dad.

I think most people have at least one person that they would do anything for, for whom they would "move heaven and earth." Well, I'm that loved one for my parents. To this day, there is no one I value or respect more than my parents. I think they really did move heaven and earth for me, as much as they could anyway, to make sure that I not only survived my years of illness but had some joy along the way.

When I was stuck in a hospital bed for weeks to control pain, recover from surgeries, or have intravenous antibiotics infused for infections, my parents were always there. One thing that sticks in my mind is how they always got me exactly what I wanted to eat. Hospital food can be okay, but when you spend weeks of your life in the same hospital with the same food, you get tired of it very quickly.

Whenever I was admitted to the hospital I would quickly start losing weight because I just wouldn't eat. It wasn't that I refused to eat; I just didn't ever eat much of my food and sometimes I wouldn't eat at all just because I didn't ever feel hungry. So as often as they could, my parents would get me something outside of the hospital to eat. They would bring me something I loved from home or a special food that I liked from a restaurant.

They tried other ways to keep me happy. My mom brought me tons of books, and my dad brought me a portable DVD player because there were only a few television channels available. Even though I read a lot, sometimes I was too sick to do anything but watch the TV screen. So my parents would bring me all kinds of funny or thought-provoking movies, and they and my brothers and I would watch those movies together and we'd talk about them afterwards and try to forget about how hard our life really was when I got so sick.

There are countless more stories like these for my parents, and they all involve the ways that they wholeheartedly gave me their affirmation, their support, and their nurturing love. Through their words and their actions they always have shown me how important I am to them, how committed they are to me.

They made me think: If my parents were willing to fight as hard as they did for me, how could I not fight for myself? Yes, my parents were the second piece of the puzzle to my willpower and my success. Both of those alone may have been enough to get me through, but I think it would have been twice as hard if I didn't have the third piece to the puzzle: my doctors. Without their care, their commitment, and their abilities, we would have had to struggle even more than we did.

Yes, my doctors are the third reason I made it through. How many of you know your doctors on a first-name basis? Do you receive cards, gifts, hugs, and phone calls from them? That is the kind of relationship my family and I have with our doctors. Dr. Virginia Pascual, Dr. Lynn Punaro, Dr. Carol Wise, and Dr. Dan

Sucato are the names on my "team." These special people have been seeing me at Scottish Rite Hospital since I was 6 years old. My condition is called PAPA syndrome, and only a few other families in the United States have it. It's a genetic disease, passed down from my dad's side of the family. The syndrome is basically inflammation everywhere, like arthritis, except with PAPA you can get it in the skin or soft tissues.

Of course, the actual diagnosis is only a few years old. Before that, most doctors didn't know how to help me, but my Dallas doctors always tried. There have been several new discoveries in medicine that may eventually make my way of living even better than it is now, but it didn't seem like much could be done for me until the last few years. My wounds are famous cases (sort of) in medical journals and in the huge files (there are now at least 13 of them) they keep on me at Scottish Rite.

Many doctors tried to figure me out, but Scottish Rite took me on, and my doctors did everything they could to help us. When research started to look promising, they would give us updates. When new medicines came out and it looked like there was even a slight chance they would work, they would do their best to get them for me. They would work with us and listen to us and try whatever looked like even a remote possibility for helping to stop my chronic inflammation and horrific wounds.

I had countless surgeries in an effort to reduce my lesions or to stop them before they became wounds and other procedures to stop the inflammation in my joints. Dr. Sucato always made me feel like he was happy to see me, no matter how busy his surgery schedule was. That counted for a lot with me and my whole family.

It was new drugs, new research, the commitment of the doctors, and my parents' tenacity that, I believe, allowed us to finally obtain new medications and start a new and better life. My willpower, my family, and my doctors—they are all essential pieces in the puzzle that has been my life so far. Without all three, there would be no success, no triumphant story, no me. I truly thank all three of them for helping me get this far.

Now, at age 19, most aspects of my health are better than they have been since I was a very small child, though I'm still not done with my journey. I have made it through some bad times, and I do know that there are still some yet to come. However, these days I'm going to college classes, hanging out with friends, and trying new things when I can. I have become even more resolved to beat my disease and have a somewhat normal life. I am aiming for a graduate degree in library science, or maybe I'll decide to be an English teacher. I do have plans for the future, and that alone is enough to keep me going.

We all have fears, troubles, or pain that we must overcome. I'm only one small example of what each and every one of us is capable of. So if you are climbing your own mountain in your life right now, fear not, for you will get to the other side and you will reach your goal. We never say die, for we are strong and we are, in the end, unbeatable. So thank you for the award you have given me today, and remember that every person who overcomes challenges and stays positive deserves an award of their own too.